

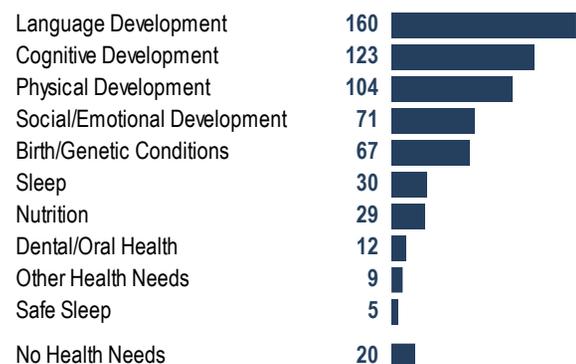
# Children & Youth with Special Healthcare Needs (CYSHCN)

Definition: Children and/or adolescents (1-21 years old) who have or are at increased risk for chronic physical, developmental, behavioral, or emotional conditions and who also require health and related services of a type or amount beyond that required by children generally. In the Statewide Survey, CYSHCN included three different age categories.

## Young Child (0-5 Years Old)

### Needs from Statewide Survey

Out of 280 responses, parents/caregivers shared that the following were needs for their young child:



## Child (6-12 Years Old)

### Needs from Statewide Survey

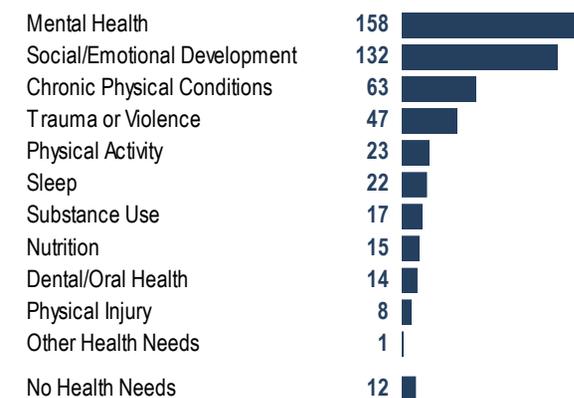
Out of 233 responses, parents/caregivers shared that the following were needs for their child:



## Adolescent (13-21 Years Old)

### Needs from Statewide Survey

Out of 224 responses, parents/caregivers shared that the following were needs for their adolescent:



## Needs from Secondary Data



10% of all Indiana children ages 3-5 have been diagnosed with a developmental delay (IYI KIDS COUNT® Data Book, 2020).



Among the services provided by First Steps to children 0-3 years old, 63% of children received speech therapy, 54% received developmental therapy, 54% received occupational therapy, and 50% received physical therapy (Indiana Family and Social Services Administration (2019) from IYI KIDS COUNT® Data Book, 2020).



37% of Indiana children 3-17 with special healthcare needs have been diagnosed with Attention Deficit Disorder (ADD) or Attention Deficit Hyperactivity Disorder (ADHD) (NSCH, 2017-2018).



Indiana (3.5%) has the highest percentage of children who have ever been diagnosed with an Autism spectrum disorder when compared with other Midwestern states of Michigan (3.2%), Illinois (3.1%), Kentucky (2.6%), and Ohio (2.7%), and compared to the US overall (3.0%) (NSCH from IYI KIDS COUNT® Data Book, 2020).



70% of children 12-17 with special healthcare needs have been bullied. This is higher than children of the same age without special healthcare needs (30%) and higher than CYSHCN across the nation (56%) (NSCH, 2018).

\*\*Statewide survey data are from 2020 and focus groups were conducted in 2019 & 2020; both caregivers' feedback about the needs of their child or young adult with special healthcare needs.

# CYSHCN *(continued)*

Definition: Children and/or adolescents (1-21 years old) who have or are at increased risk for chronic physical, developmental, behavioral, or emotional conditions and who also require health and related services of a type or amount beyond that required by children generally. In the Statewide Survey, CYSHCN included three different age categories.

## Young Child (0-5 Years Old)

### Barriers from Statewide Survey



## Child (6-12 Years Old)

### Barriers from Statewide Survey



## Adolescent (13-21 Years Old)

### Barriers from Statewide Survey



\*\*Overall Barriers and Resources counts are an aggregate of Barriers and Resources responses across all needs for each CYSHCN age group.

### Barriers from Focus Groups

Prominent barriers for focus group participants included not having enough local service providers, a lack of health insurance or health insurance coverage, and challenges accessing specialty healthcare services.

*"We have to travel to see specialists. We have to go all the way up to Indy or Riley [from southwest Indiana] for three different specialists."*

*"Just even getting into an appointment that's after school hours are difficult because they close at 5 and only have so many [appointment times] and they get booked up the fastest and so that's more of what I'm talking about. It's just difficult."*

*"Most insurance, I would say most, but I don't think every insurance is that way, but my private insurance would not cover autism."*

## Young Child (0-5 Years Old)

### Resources from Statewide Survey



## Child (6-12 Years Old)

### Resources from Statewide Survey



## Adolescent (13-21 Years Old)

### Resources from Statewide Survey



### Resources from Focus Groups

Resources shared during focus groups included the internet (e.g., Google), doctors and other healthcare workers, and personal motivation (e.g., determination).

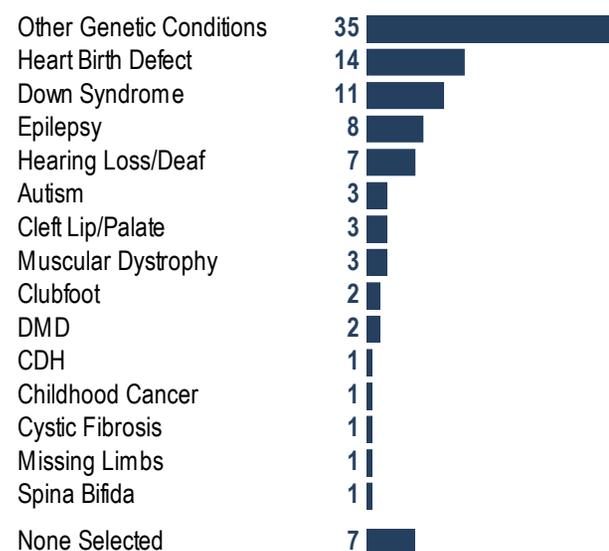
*"I try to find group forums now of people who have tried certain medicines or tried different things and [then share about] what they've experienced, cause they've already tried it. [I like] to see if it's worked for them or not."*

\*\*Statewide survey data are from 2020 and focus groups were conducted in 2019 & 2020; both caregivers' feedback about the needs of their child or young adult with special healthcare needs.

# Birth/Genetic Conditions

Definition: Genetic conditions or birth defects, including Down syndrome, heart defects, or spina bifida.

## Statewide Survey: Birth/Genetic – Described



## “Other Genetic Conditions” – Described

When five or more of the same condition existed in “Other Genetic Conditions,” these were pulled out of “other” and into their own category. Examples of “other” conditions with fewer than five responses included:

- Beckwith-Wiedemann syndrome
- Cerebral palsy
- Chromosomal abnormality
- Colpocephaly
- Cowden's syndrome
- Diaphragmatic eventration
- Epidermolysis bullosa simplex (EBS)
- Hereditary spherocytosis
- Hirschsprung's
- Idiopathic infantile scoliosis
- Microcephaly
- Symbrachydactyly
- Trigenocephaly
- Usher syndrome

## Statewide Survey: Birth/Genetic Barriers



## Focus Group Quotes

“[The hospital’s doctors, nurses, and staff have] been really good, especially with him having Down syndrome. They tell me about these wait rooms they have and different insurance you can get. They even reminded me over and over and over again before I left [the hospital]. Then I saw the pediatrician and because there’s so long of a waiting list for it, they were telling me about that and that it’s really hard to get.” – [Birth/Genetic Conditions](#)

“[Providers] just kept blowing me off and then my daughter came out with her bone missing in her leg. I found out later on that they could go in my stomach with a needle and do steroid shots for the baby and she would’ve had a chance at growing that bone.” – [Birth/Genetic Conditions](#)

## Quick Facts

**3%** of Indiana children ages 3-17 were diagnosed with an Autism spectrum disorder (NSCH, 2017-2018).

**92%** of babies born in Indiana in 2019 were screened for a birth defect. This is relatively similar to screening rates in previous years (94% in 2018, 95% in 2017 and 2016, and 92% in 2015) (ISDH GNBS, 2015-2019).

**80** of every 10,000 male babies in Indiana in 2018 were born with hypospadias. This rate has increased since 2014 (41) (ISDH GNBS, 2014-2018).

**61** of every 10,000 babies in Indiana in 2018 were born with atrial septal defect. This rate has decreased since 2016 (129) (ISDH GNBS, 2016-2018).

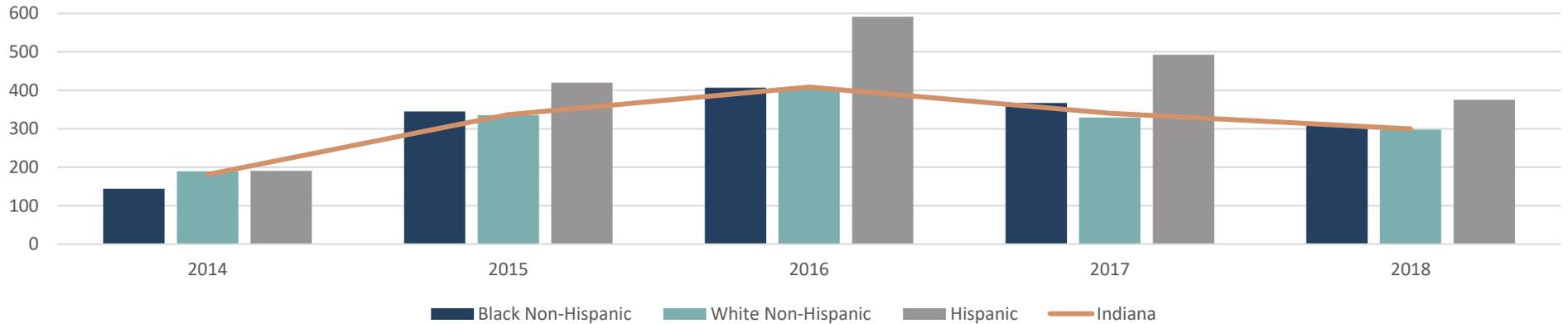
# Birth/Genetic Conditions (continued)

Definition: Genetic conditions or birth defects, including Down syndrome, heart defects, spina bifida.

## Quick Facts (continued)

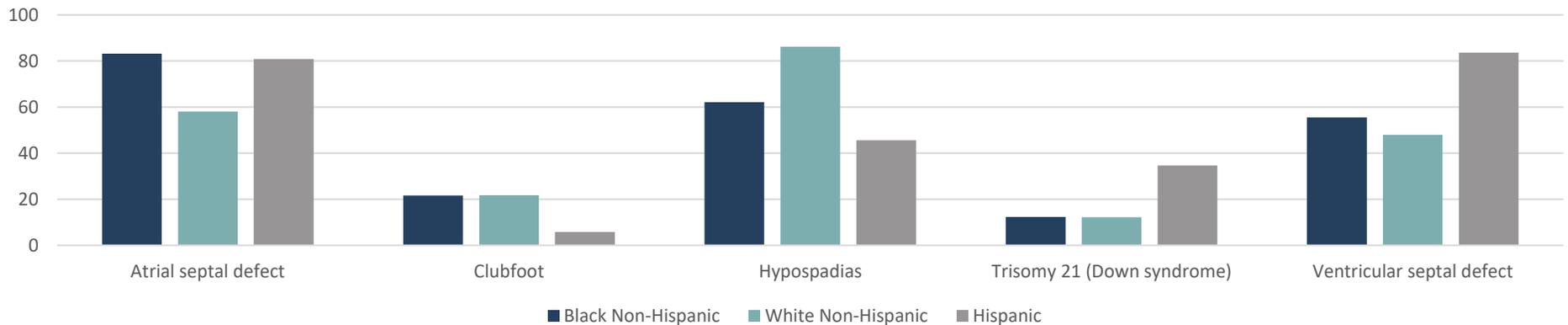
The rate of infants born with a birth defect in **Indiana** has *decreased* since 2016.

**Hispanic babies** have *higher* rates of birth defects than **White Non-Hispanic babies** and **Black Non-Hispanic babies** (rate per 10,000 live births).



Data Source: ISDH Genomics and Newborn Screening, 2014-2018

The rate of babies born with one of the five most common birth defects in Indiana in 2018 are shown below (rate per 10,000 live births).



Data Source: ISDH Genomics and Newborn Screening, 2018

\*Rate for Hypospadias is per 10,000 live male births.

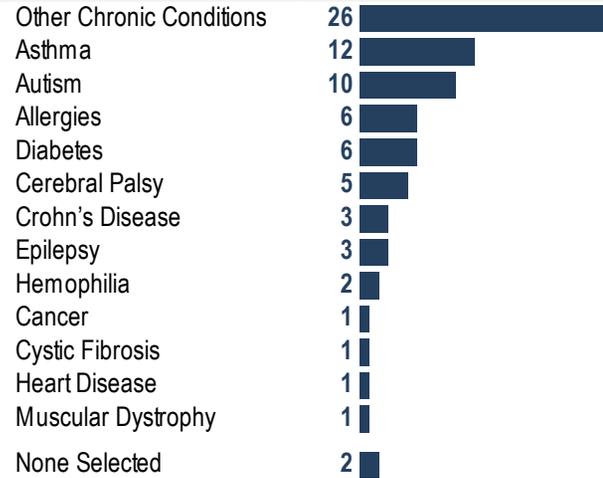
\*\*Statewide survey data are from 2020 and focus groups were conducted in 2019 & 2020; both caregivers' feedback about the needs of their child or young adult with special healthcare needs.

# Chronic Physical Conditions

Definition: Longer-term physical conditions, such as chronic pain, diabetes, cancer, allergies, asthma, chronic ear infections, or sleep apnea.

## Statewide Survey – Child

### Chronic Physical Conditions – Described



### “Other Chronic Conditions” – Described

When five or more of the same condition existed in “Other Chronic Conditions,” these were pulled out of “other” and into their own category. Examples of “other” conditions with fewer than five responses included:

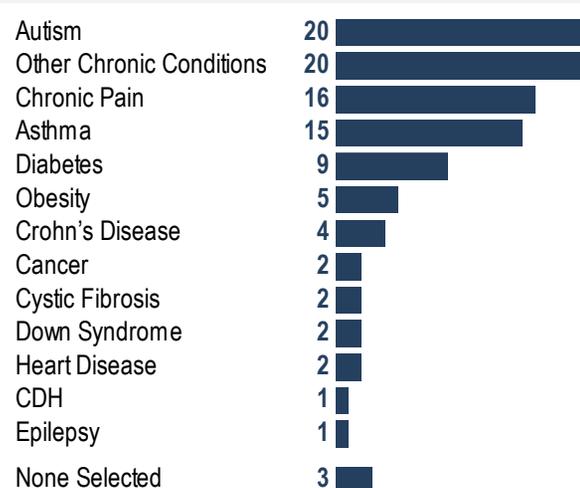
- Cataracts
- Celiac disease
- CHARGE syndrome
- Chronic migraine
- Congenital amputee
- Hearing impairment
- Kidney disease
- Nephrotic syndrome
- Noonan syndrome
- Pulmonary hypoventilation
- Severe eczema
- Tourette syndrome

### Chronic Physical Conditions Barriers



## Statewide Survey – Adolescent

### Chronic Physical Conditions – Described

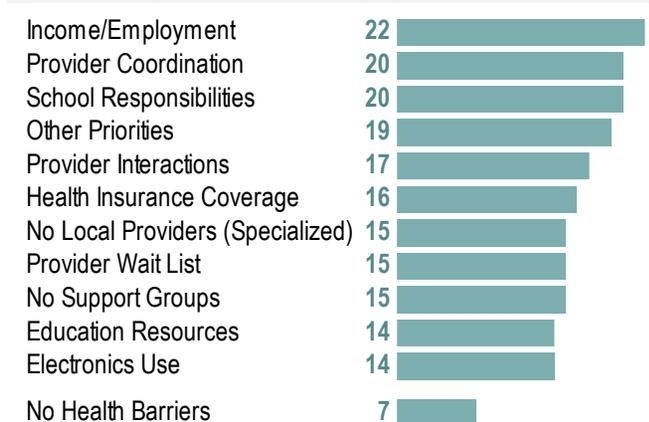


### “Other Chronic Conditions” – Described

When five or more of the same condition existed in “Other Chronic Conditions,” these were pulled out of “other” and into their own category. Examples of “other” conditions with fewer than five responses included:

- Antiphospholipid antibody syndrome
- Arthritis juvenile
- Celiac disease
- Cerebral palsy
- Cystinuria
- Ehlers-Danlos syndrome (EDS)
- Eosinophilic esophagitis
- Hearing loss
- High blood pressure
- Irritable bowel syndrome (IBS)
- Lyme disease
- Thyroid disorder

### Chronic Physical Conditions Barriers



\*\*Statewide survey data are from 2020 and focus groups were conducted in 2019 & 2020; both caregivers’ feedback about the needs of their child or young adult with special healthcare needs.

# Chronic Physical Conditions *(continued)*

Definition: Longer-term physical conditions, such as chronic pain, diabetes, cancer, allergies, asthma, chronic ear infections, or sleep apnea.

## Focus Group Quotes

“[My son has] got a lot of GI issues and they were just like, ‘oh, he’s probably dehydrated or constipated.’ I’m like, ‘no, he has chronic diarrhea.’” – **Chronic Physical Conditions**

“[My son] has a heart issue.” – **Chronic Physical Conditions**

“I’ve taken my son for [health] issues and I think they’re quite serious.” – **Chronic Physical Conditions**

“When we saw some symptoms [we] didn’t know if it was stemming from autism, or Tourette’s, and we knew there were some OCD behaviors. We wanted him evaluated... We’re dealing with OCD. And we’re concerned that he may have Tourette’s. And we need somebody that can differentiate between [those and autism].” – **Chronic Physical Conditions**

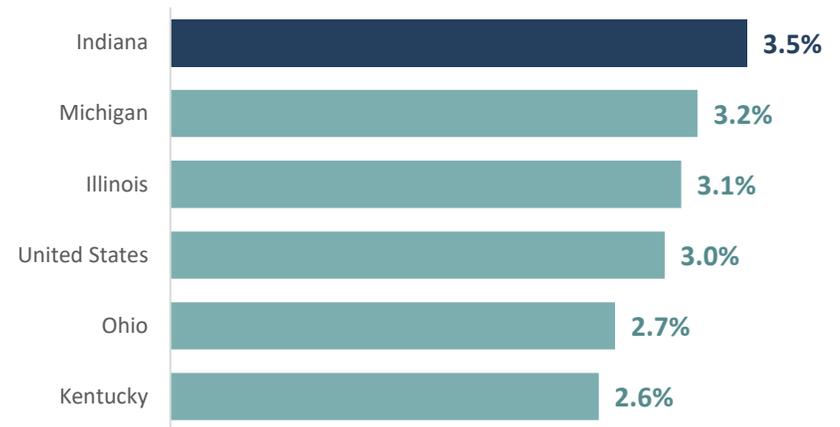
“[My child] has OCD and Tourette’s.” – **Chronic Physical Conditions**

“We have a few autism places but there’s not a lot of places who will take kids with sensory processing disorder for occupational therapy. The one [local provider], they’re usually pretty full. Like you said, people have to travel to take their kids to occupational therapists.” – **Barrier: No Local Providers (Specialized)**

## Quick Facts

The prevalence of Autism in **Indiana** is the *highest* compared to other **Midwestern states** and the **US**.

(Percent of children 3-17 who have ever been diagnosed with an autism spectrum disorder)



Data Source: NSCH from IYI KIDS COUNT® Data Book, 2020

# Cognitive Development

Definition: Delays in development for babies/young children (following directions, scribbling, imitating others, learning numbers) or children 6-12 (focusing attention, following complex commands).

## Statewide Survey:

### Cognitive Development Barriers – Young Child



## Statewide Survey:

### Cognitive Development Barriers – Child



## Focus Group Quotes

“I’m a mom to a kindergartener with learning needs.” – **Cognitive Development**

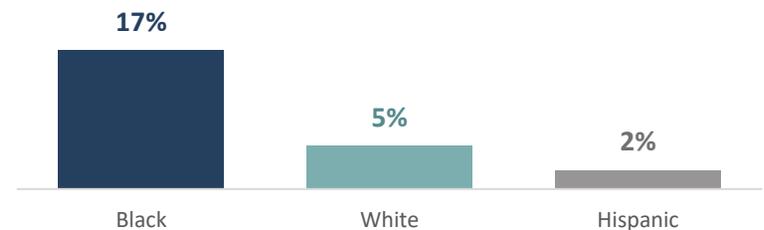
“There’s not a lot of information really out there at all about early intervention. I mean I remember with my first [child] it really wasn’t talked about. You can have any child evaluated for early intervention services and nobody tells you that.” – **Barrier: Education About Resources**

“Getting into an appointment that’s after school hours [is] difficult, because they close at 5 and only have so many [openings].” – **Barrier: Provider Wait List**

## Quick Facts

- 10%** of all Indiana children ages 3-5 have been diagnosed with a developmental delay (IYI KIDS COUNT® Data Book, 2020).
- 27%** of Indiana children 9-35 months received a developmental screening using a parent-completed screening tool in the past year, compared to 34% of children nationally (NSCH, 2017-2018).
- 14%** of Indiana Head Start preschoolers have an Individualized Education Plan (IEP), and 17% of Head Start infants and toddlers have an Individualized Family Services Plan (IFSP) (Office of Head Start PIR Summary Report, 2018).
- 73%** of Indiana children 3-5 years old who are enrolled in special education through IDOE are White, compared to Hispanic (11%) and Black (9%) (IDOE, 2019).

A larger percentage of **Black children** ages 3-17 were diagnosed with a developmental delay.



Data Source: NSCH from IYI KIDS COUNT® Data Book, 2020

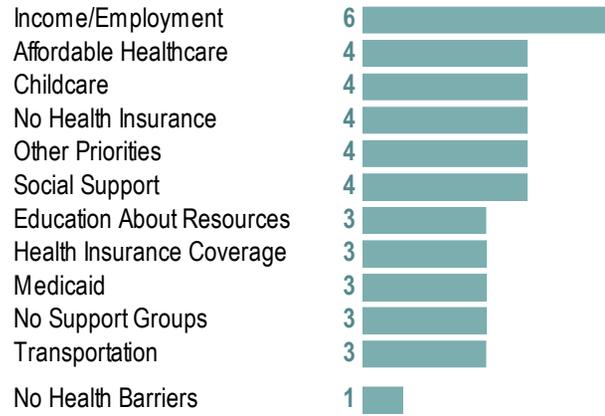
\*\*Statewide survey data are from 2020 and focus groups were conducted in 2019 & 2020; both caregivers’ feedback about the needs of their child or young adult with special healthcare needs.

# Dental/Oral Health

Young Child **#8**, Child **#6**, & Adolescent **#9**

Definition: Oral health needs, including regular check-ups and dental surgery.

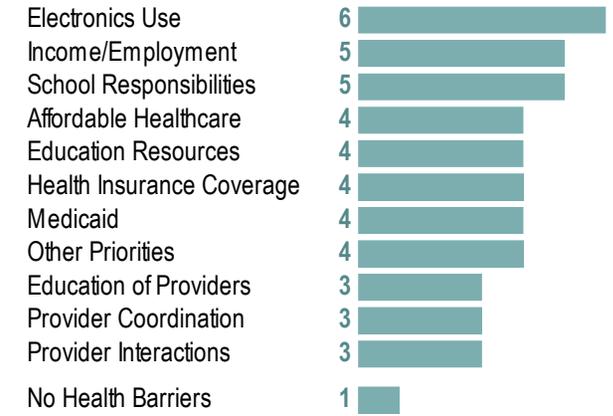
## Statewide Survey: Dental/Oral Health – Young Child



## Statewide Survey: Dental/Oral Health – Child



## Statewide Survey: Dental/Oral Health – Adolescent



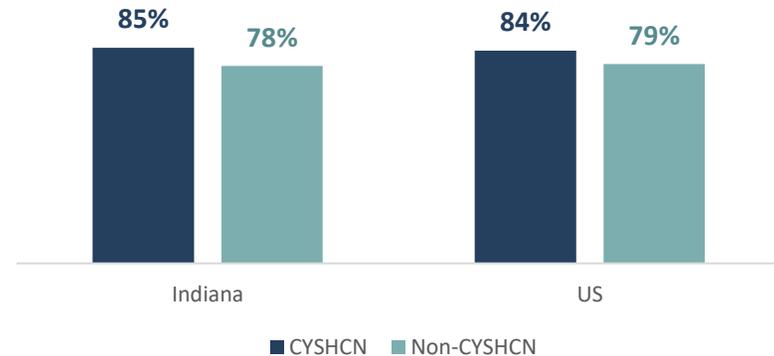
## Focus Group Quotes

“My husband works full time and we still struggle with meeting our [needs]. I mean right off the bat, we hit our deductible... There’s a secondary insurance you can get if your child has a critical illness, which we would qualify for if we didn’t make too much money. We’re always right above that [income] bracket... We fall into the needy and there’s no help.” – **Barrier: Income/Employment**

“Even with the new Medicaid, the way it works for working families, it’s supposed to go by income [but] you still cannot afford those copays. Especially when you have four children and they all get sick at the same time. So just thinking about that, just making things work and when you have working adults, even if they work for the state of Indiana and have children and still cannot afford copays.” – **Barrier: Affordable Healthcare**

## Quick Facts

Children and youth with special healthcare needs (CYSHCN) in Indiana have a higher percentage of attending one or more preventative dental visits in the past year, compared to CYSHCN across the US and to non-CYSHCN.



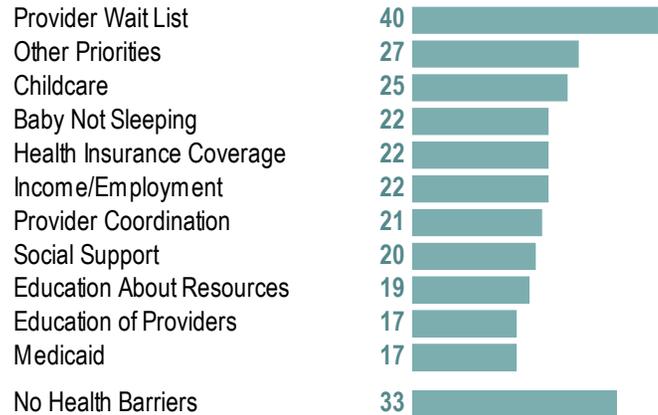
Data Source: National Survey of Children’s Health, 2017-2018

\*\*Statewide survey data are from 2020 and focus groups were conducted in 2019 & 2020; both caregivers’ feedback about the needs of their child or young adult with special healthcare needs.

# Language Development

Definition: Delays in language development, such as speaking clearly or telling stories.

## Statewide Survey: Language Development Barriers



## Focus Group Quotes

*"I'm doing what I can with [my son]. But I'm mom; he communicates with me without words. It's where he's getting frustrated with other people cause they're not understanding his nods, or weird cues." – Language Development*

*"If someone cannot do these [speech] therapies, or have somebody come to them, or whatever the situation is, you can at least leave [me] with some sort of resource. 'Hey, look up online, maybe if you work on some of these vocal tones with them, or you know, muscle exercises,' at least give [me] something... I feel like I'm failing him, but I can't help it." – Language Development*

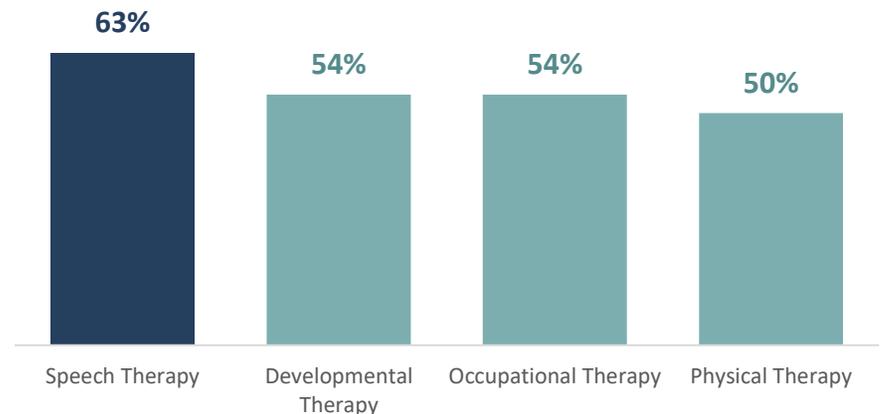
*"My son [was] in speech at school." – Language Development*

*"Getting into an appointment that's after school hours [is] difficult, because they close at 5 and only have so many [openings] and they get booked up the fastest" – Barrier: Provider Wait Lists*

## Quick Facts

- 10%** of Indiana Head Start preschool children were diagnosed with a speech or language impairment (Office of Head Start PIR Summary Report, 2018).
- 36%** of Indiana parents of children 0-5 years old have been asked by their child's doctor if they have concerns about their child's learning, development, or behavior (NSCH from IYI KIDS COUNT® Data Book, 2020).
- 27%** of Indiana children 9-35 months received a developmental screening using a parent-completed screening tool in the past year, compared to 34% of children nationally (NSCH, 2017-2018).
- 10%** of all Indiana children ages 3-5 have been diagnosed with a developmental delay (IYI KIDS COUNT® Data Book, 2020).
- 17%** of Indiana's Black children ages 3-17 were diagnosed with a developmental delay, compared to 5% of White, 2% of Hispanic, and 6% of children of other races (NSCH from IYI KIDS COUNT® Data Book, 2020).

The majority of children 0-3 years old served by First Steps received **Speech Therapy**.



Data Source: Indiana Family and Social Services Administration (2019) from IYI KIDS COUNT® Data Book, 2020

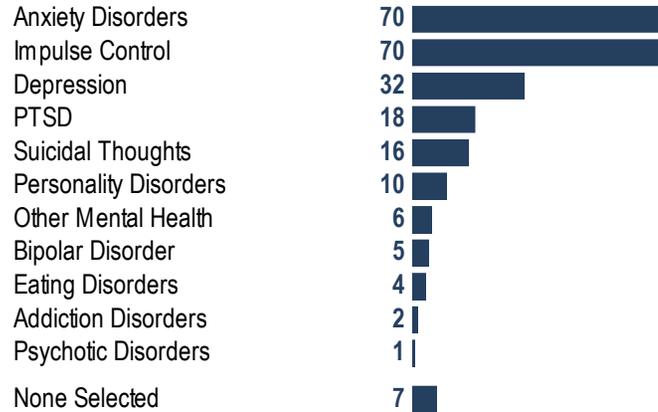
\*\*Statewide survey data are from 2020 and focus groups were conducted in 2019 & 2020; both caregivers' feedback about the needs of their child or young adult with special healthcare needs.

# Mental Health

Definition: Mental health needs, including depression, anxiety, or other conditions.

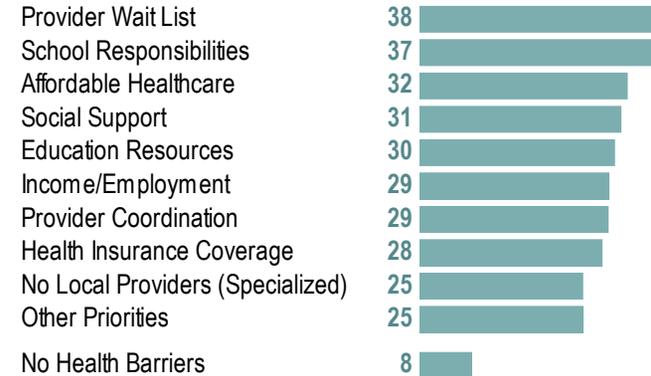
## Statewide Survey – Child

### Mental Health – Described



“Other Mental Health” contains responses including adjustment disorder, disruptive mood dysregulation disorder (DMDD), poor social/emotional executive functioning, and reactive attachment.

### Mental Health Barriers



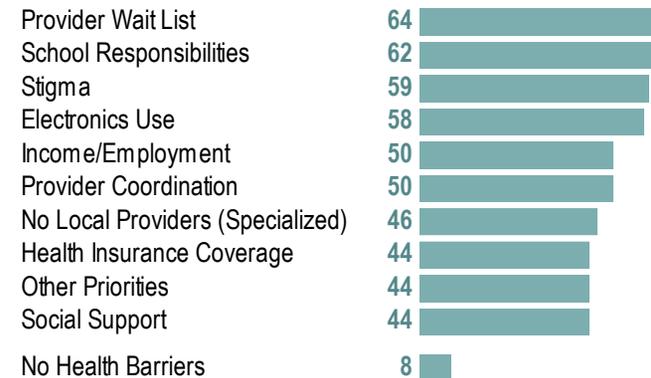
## Statewide Survey – Adolescent

### Mental Health – Described



“Other Mental Health” contains responses including gender dysphoria, self-harming, and suicide attempts.

### Mental Health Barriers



\*\*Statewide survey data are from 2020 and focus groups were conducted in 2019 & 2020; both caregivers’ feedback about the needs of their child or young adult with special healthcare needs.

# Mental Health *(continued)*

Definition: Mental health needs, including depression, anxiety, or other conditions.

## Focus Group Quotes

“Finding doctors who will do medication management is very difficult. When you get into mixing [medications] it seems like the pediatrician will do like, ‘okay, we can treat you for ADHD or maybe we can treat you for anxiety,’ but when you start needing the combined stuff and you start getting too high in doses they just they back off, they’re not comfortable with it.” – **Mental Health**

“I think our mental health is severely lacking for kiddos. It’s so hard... very few therapists will see the special kiddos. A lot of them have to go to Indy.” – **Mental Health with Barrier: Provider Wait List**

“I mean the hardest thing is getting diagnosed and then having a waitlist. There’s a waitlist to be evaluated and now we have the diagnosis now there’s a waitlist for services and it’s like all this wasted time.” – **Barrier: Provider Wait List**

## Quick Facts

**37%** of Indiana children 3-17 with special healthcare needs have been diagnosed with Attention Deficit Disorder (ADD) or Attention Deficit Hyperactivity Disorder (ADHD) (NSCH, 2017-2018).

**63%** of Indiana children 3-17 with special healthcare needs who have a mental or behavioral condition received treatment or counseling (NSCH, 2017-2018).\*  
\*estimate has a 95% confidence interval width exceeding 20 percentage points

*Mental Health statistics for all Indiana children (not only CYSHCN):*

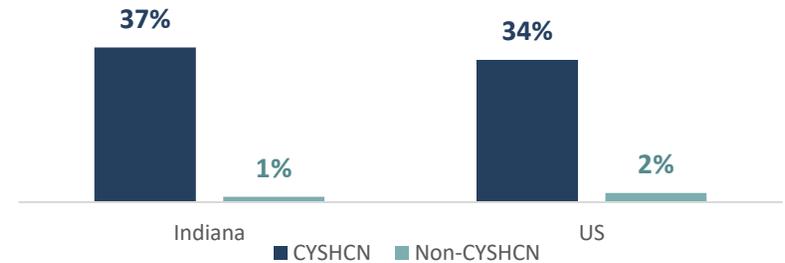
**28%** of Indiana adolescents ages 12-17 and 27% of children ages 6-11 had a mental, emotional, developmental, or behavioral problem (NSCH, 2017-2018).

**49%** of Indiana children ages 3-17 with a mental or behavioral condition received counseling (NSCH, 2017-2018).

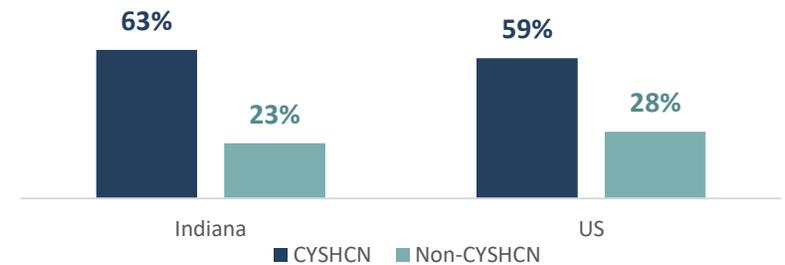
**31.6** per 10,000 Indiana adolescents ages 10-17 were hospitalized for major depressive disorders. This was the leading cause for adolescent inpatient hospitalization, followed by depression (14.2 per 10,000) and bipolar disorders (13.1 per 10,000) (ISDH Epidemiology Resource Center, 2018).

**20%** of high school students seriously considered attempting suicide (during the 12 months before the YRBS 2015 survey). This was highest for 9<sup>th</sup> grade girls (29%) (YRBS, 2015).

A larger percentage of **CYSHCN** in Indiana have been diagnosed with ADD/ADHD, compared to CYSHCN in the US and **non-CYSHCN**.



A larger percentage of **CYSHCN** in Indiana with a mental or behavioral condition received treatment, compared to CYSHCN in the US and **non-CYSHCN**.



Data Source: National Survey of Children’s Health, 2017-2018

\*\*Statewide survey data are from 2020 and focus groups were conducted in 2019 & 2020; both caregivers’ feedback about the needs of their child or young adult with special healthcare needs.

# Nutrition

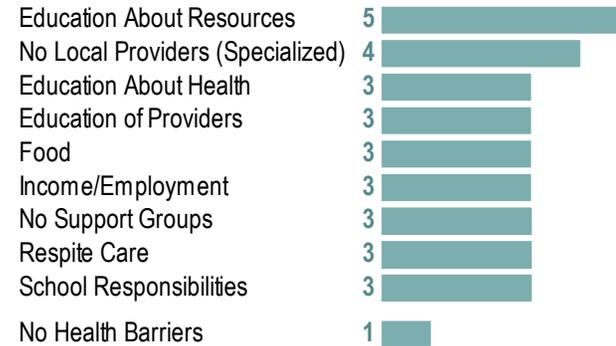
Young Child #7, Child #8, & Adolescent #8

Definition: Poor nutrition, including lacking breast milk (baby/young child), formula (baby/young child), solids, or other foods.

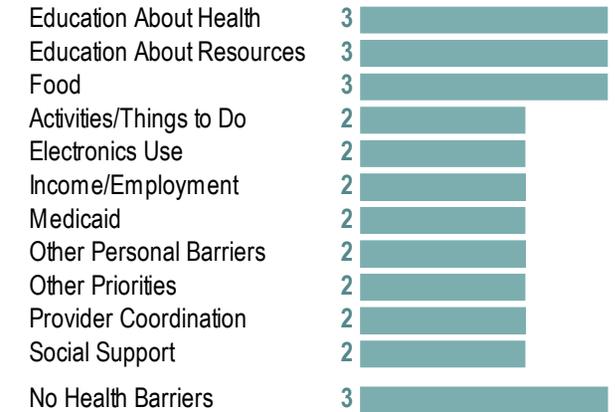
## Statewide Survey: Nutrition – Young Child



## Statewide Survey: Nutrition – Child



## Statewide Survey: Nutrition – Adolescent



## Focus Group Quotes

*“I think that this issue lies with what we have [eaten in our] past, high sugar diets and our French fries and fast food stuff and stuff on the shelf that’s highly processed. People who maybe are at the higher end of the income scale have access to better food choices than a lot of us who are not able to do that. We don’t have the skill set to make those selections. It’s easier to eat the cheap food, which is what it is. That leads to all sorts of weight issues, diabetes, which all that adds to more trauma. We need to figure out how to get better nutrition for people who don’t get to make those choices for themselves.” – Nutrition*

*“I think it would be more helpful to have more nutrition information for parents [such as] what their kids need to be eating, or how to help picky eaters or eating issues.” – Barrier: Education About Health (Focus group not specific to CYSHCN)*

*“We have to travel to see specialists. We have to go all the way up to Indy or Riley for three different specialists.” – Barrier: No Local Providers (Specialized)*

## Quick Facts

**37%** of Indiana families with children with special healthcare needs said, “We could always afford to eat, but not always the kinds of food we should eat.” In comparison, 58% families with CYSHCN said, “We could always afford to eat good, nutritious meals,” (NSCH, 2017-2018).

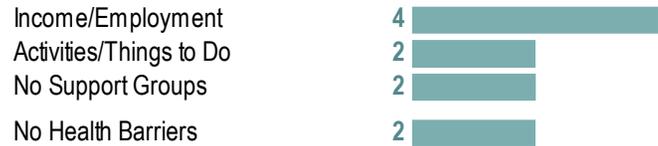
**43%** of Indiana families with children with special healthcare needs received at least one form of food or cash assistance (NSCH, 2017-2018).

*\*\*Statewide survey data are from 2020 and focus groups were conducted in 2019 & 2020; both caregivers’ feedback about the needs of their child or young adult with special healthcare needs.*

# Physical Activity

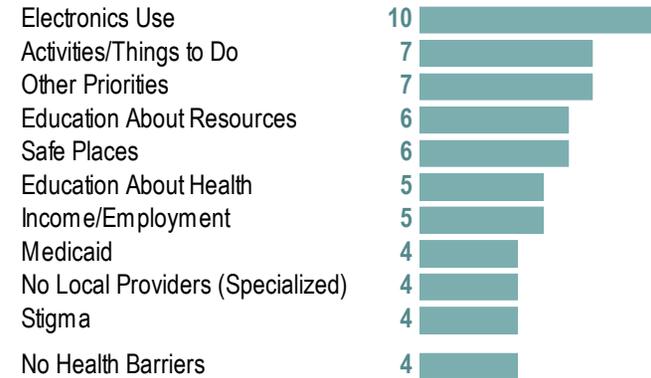
Definition: Physical needs related to a lack of physical activity or physical movement.

## Statewide Survey: Physical Activity Barriers – Child



14 barriers had "1" response, so only the top 3 are displayed

## Statewide Survey: Physical Activity Barriers – Adolescent



## Focus Group Quotes

"We're outsourcing an unbelievable amount of money to things. We're hitting credit card after credit card because we don't have the funds to pay on our bills and everything that we have to have to live." – **Barrier: Income/Employment**

"[Teens] just get on [their phones] and don't quit texting. Video games. Netflix. Snapchat. Tik Tok." – **Barrier: Personal Choices with Electronics** (From adolescent focus group)

"There's nothing to do." – **Barrier: Limited Activities/Things to Do** (From adolescent focus group)

"I don't necessarily have time." – **Barrier: Other Priorities**

## Quick Facts

- 51%** of Indiana children ages 6-11 with special healthcare needs receive less than 60 minutes of physical activity for 4 or more days during the week (NSCH, 2017-2018).
- 69%** of Indiana teens ages 12-17 with special healthcare needs receive less than 60 minutes of physical activity for 4 or more days during the week (NSCH, 2017-2018).
- 16%** of Indiana children ages 10-17 with special healthcare needs are obese, and another 16% are overweight (NSCH, 2017-2018).
- 35%** of Indiana families with children with special healthcare needs do not live in a neighborhood where there is a park or playground (NSCH, 2017-2018).
- 59%** of Indiana parents of children ages 0-17 years old with special healthcare needs definitely agree that their child lives in a safe neighborhood, compared to 72% for children without special healthcare needs (NSCH, 2017-2018).

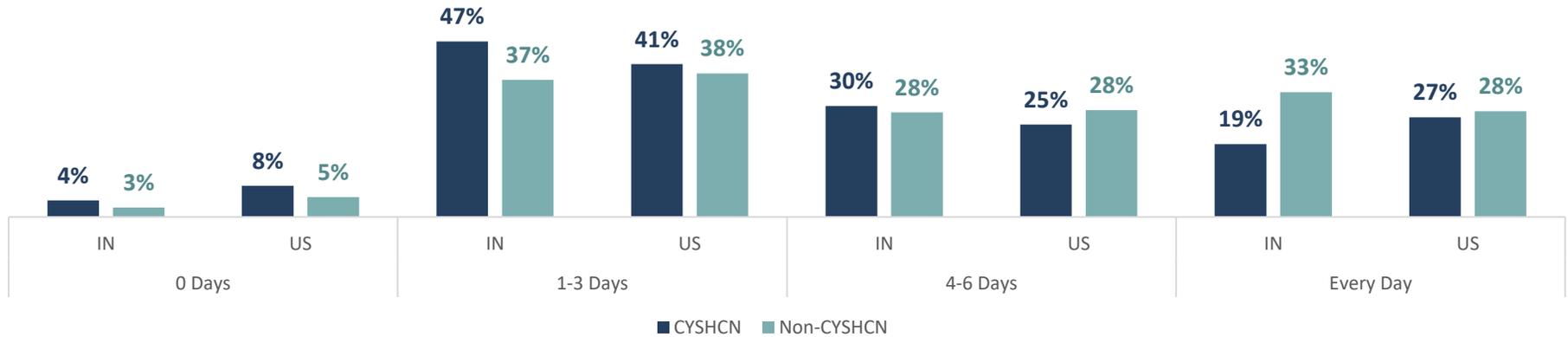
\*\*Statewide survey data are from 2020 and focus groups were conducted in 2019 & 2020; both caregivers' feedback about the needs of their child or young adult with special healthcare needs.

# Physical Activity *(continued)*

Definition: Physical needs related to a lack of physical activity or physical movement.

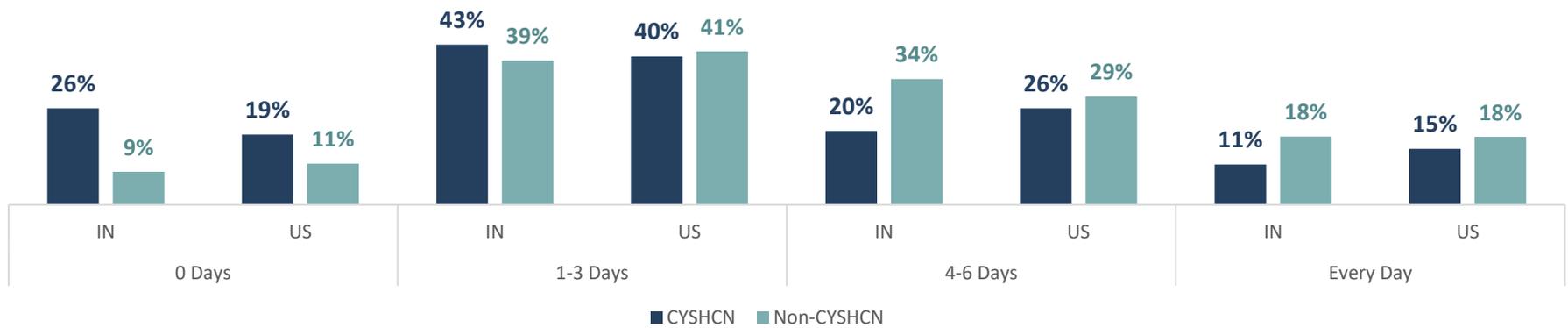
## Quick Facts *(continued)*

The percentage of children, ages 6-11, who are physically active at least 60 minutes per day each week. **CYSHCN** in Indiana have *lower* physical activity levels than both CYSHCN in the US and **non-CYSHCN**.



Data Source: National Survey of Children's Health, 2017-2018

The percentage of adolescents, ages 12-17, who are physically active at least 60 minutes per day each week. **CYSHCN** in Indiana have *lower* physical activity levels than both CYSHCN in the US and **non-CYSHCN**.



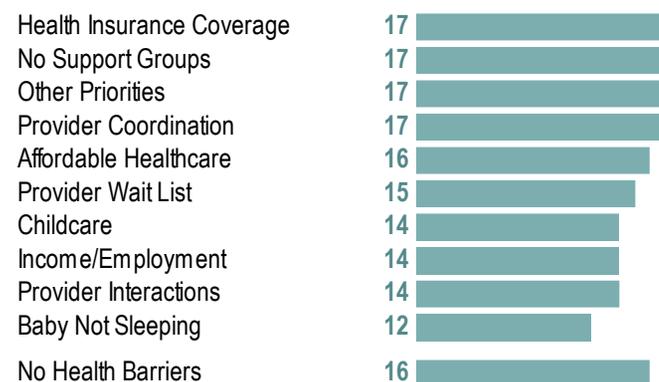
Data Source: National Survey of Children's Health, 2017-2018

\*\*Statewide survey data are from 2020 and focus groups were conducted in 2019 & 2020; both caregivers' feedback about the needs of their child or young adult with special healthcare needs.

# Physical Development

Definition: Delays in physical development or activity, such as tummy time, crawling, walking, jumping, or catching a ball.

## Statewide Survey: Physical Development Barriers



## Focus Group Quotes

"[My daughter] needs [occupational therapy] weekly." – **Physical Development**

"She couldn't chew food at a year old." – **Physical Development**

"[My husband] switched jobs, and his new insurance has a number limit on her therapy. So that makes me nervous but because she needs OT weekly, like, it makes me nervous that a health insurance has like a blanket number. 'Well, this is acceptable.' No, that's not acceptable for us." – **Barrier: Health Insurance Coverage**

"There's no collaboration. When my son was at Riley and seeing all his specialists, I would ask them to all talk together because I thought maybe everything was hooking together and they didn't collaborate. I would have to tell them what was happening with all the other doctors with his other issues." – **Barrier: Provider Coordination**

## Quick Facts

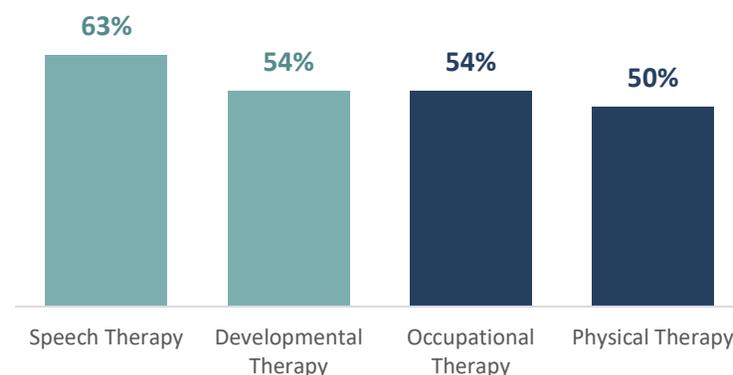
**36%** of Indiana parents of children 0-5 years old have been asked by their child's doctor if they have concerns about their child's learning, development, or behavior (NSCH from IYI KIDS COUNT® Data Book, 2020).

**27%** of Indiana children 9-35 months received a developmental screening using a parent-completed screening tool in the past year, compared to 34% of children nationally (NSCH, 2017-2018).

**10%** of all Indiana children ages 3-5 have been diagnosed with a developmental delay (IYI KIDS COUNT® Data Book, 2020).

**17%** of Indiana's Black children ages 3-17 were diagnosed with a developmental delay, compared to 5% of White, 2% of Hispanic, and 6% of children of other races (NSCH from IYI KIDS COUNT® Data Book, 2020).

The majority of children 0-3 years old served by First Steps received **Occupational Therapy** and/or **Physical Therapy**.



Data Source: Indiana Family and Social Services Administration (2019) from IYI KIDS COUNT® Data Book, 2020

# Physical Injury

Statewide Survey

Child #10 & Adolescent #10

Definition: Physical injury, such as from a car or playground accident.

## Statewide Survey: Physical Injury – Child

Less than 10 respondents identified Physical Injury as a need for their child (6-12 years old). Due to the small number of responses, specific barrier information is not included.

## Statewide Survey: Physical Injury – Adolescent

Less than 10 respondents identified Physical Injury as a need for their adolescent (13-21 years old). Due to the small number of responses, specific barrier information is not included.

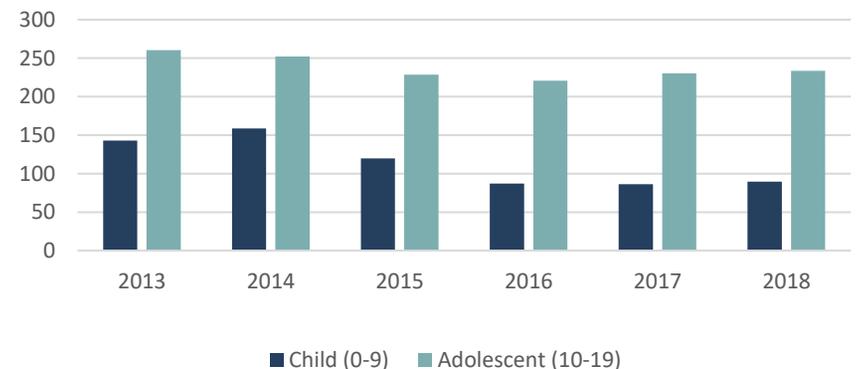
## Quick Facts

- 93%** of Indiana families with children with special healthcare needs agree that their child lives in a safe neighborhood (NSCH, 2017-2018).
- 76%** of Indiana families with children with special healthcare needs live in a neighborhood where there are sidewalks or walking paths (NSCH, 2017-2018).
- 20%** of Indiana families with children with special healthcare needs live in a neighborhood that has poorly kept or dilapidated housing (NSCH, 2017-2018).

## Physical Injury statistics for all Indiana children (not only CYSHCN):

- 234** per 100,000 Indiana adolescents ages 10-19 were hospitalized for non-fatal injuries in 2018. This group is hospitalized at higher rates than children ages 0-9 (90 per 100,000) (ISDH Epidemiology Resource Center, 2018).
- 9.9** per 100,000 Indiana adolescents ages 10-17 died from accidents (unintentional injuries), which was the leading cause of death for this age group. Children ages 0-9 died from accidents at a rate of 5.4 per 100,000, which was also the leading cause of death for this age group (ISDH Epidemiology Resource Center, 2018).
- 40%** of injury deaths for Indiana adolescents age 15-18, 23% of injury deaths for adolescents ages 12-14, and 33% of injury deaths for children ages 6-11 were transportation-related (Special Emphasis Report, 2018).

From 2013 to 2018, hospitalizations involving non-fatal injury per 100,000 persons decreased by 37% for **children ages 0-9** and 10% for **adolescents ages 10-17**.



Data Source: ISDH Epidemiology Resource Center, 2013-2018

\*\*Statewide survey data are from 2020 and focus groups were conducted in 2019 & 2020; both caregivers' feedback about the needs of their child or young adult with special healthcare needs.

# Safe Sleep

Definition: Safe sleep for infant (alone, on their back, in a crib).

## Statewide Survey: Safe Sleep Barriers

Less than 10 respondents identified Safe Sleep as a need for their baby/young child (0-5 years old). Due to the small number of responses, specific barrier information is not included.

## Focus Group Quotes

The following quotes are from focus groups that were not specific to CYSHCN:

“I did the safe sleep class.” – *Safe Sleep*

“There's nobody to talk to you about safe sleep in the hospital.” – *Safe Sleep*

“Any sort of event where they have the tables set up with the different resources, we learned about safe sleep.” – *Safe Sleep*

“Actually, I was terrified of co-sleep because of [what I had learned about safe sleep]. I was absolutely terrified to co-sleep, because I had heard all these terrible things. It wasn't until he was a year old and I got tired of getting up in the middle of the night and breastfeeding [that we started co-sleeping].” – *Safe Sleep*

“I feel like a lot of doctors are really judgy too. You're afraid to say that you co-sleep or whatever. That's not supported as safe sleep.” – *Safe Sleep*

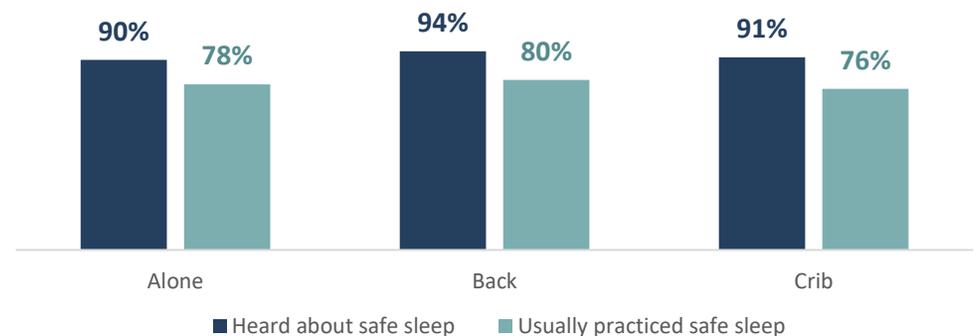
## Quick Facts (for all babies/young children)

**78%** of mothers reported that their new baby usually slept without soft objects or bedding. This safe sleep practice was higher for White Non-Hispanic mothers (81%), compared to Black Non-Hispanic mothers (64%) and Hispanic mothers (73%) (PRAMS, 2017\*).

**80%** of mothers reported that they most often laid their baby on his or her back to sleep. This safe sleep practice was higher for White mothers (88%) and lower for Black mothers (75%) (PRAMS, 2017\*).

**76%** of mothers reported that they usually placed their baby to sleep on a separate, approved sleep surface during the past two weeks. This was slightly higher for White Non-Hispanic mothers (78%), compared to Black Non-Hispanic mothers (71%) and Hispanic mothers (76%) (PRAMS, 2017\*).

Of those who participated in the PRAMS survey, most mothers reported **hearing about the ABCs of safe sleep** (Alone, Back, Crib) from a doctor, nurse, or other healthcare worker. At least 3 of every 4 mothers **reported usually engaging in safe sleep for their baby**.



Data Source: Pregnancy Risk Assessment Monitoring System, 2017\*

\*PRAMS, 2017: Estimates based on data with very low response rates (below 55%) may be less accurate or precise, and should be interpreted with caution.

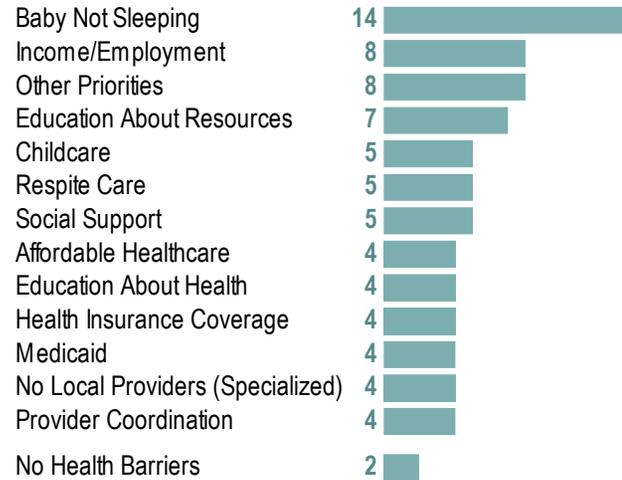
\*\*Statewide survey data are from 2020 and focus groups were conducted in 2019 & 2020; both caregivers' feedback about the needs of their child or young adult with special healthcare needs.

# Sleep

Young Child #6, Child #7, & Adolescent #6

Definition: Sleep needs, including regular, adequate sleep.

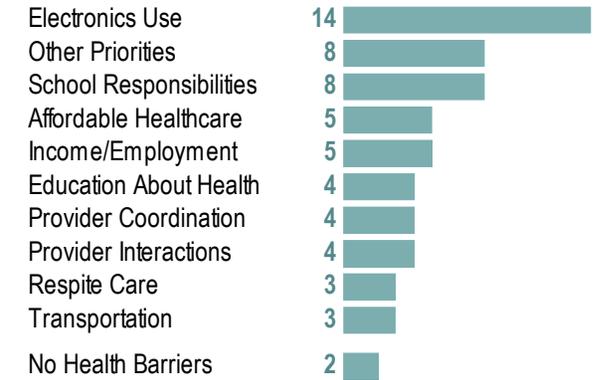
## Statewide Survey: Sleep Barriers – Young Child



## Statewide Survey: Sleep Barriers – Child



## Statewide Survey: Sleep Barriers – Adolescent



## Focus Group Quotes

“I want to sleep more, but then I feel like I’m going to miss something good in the group chat if I go to sleep.” – **Sleep with Barrier: Personal Choices with Electronics** (From adolescent focus group)

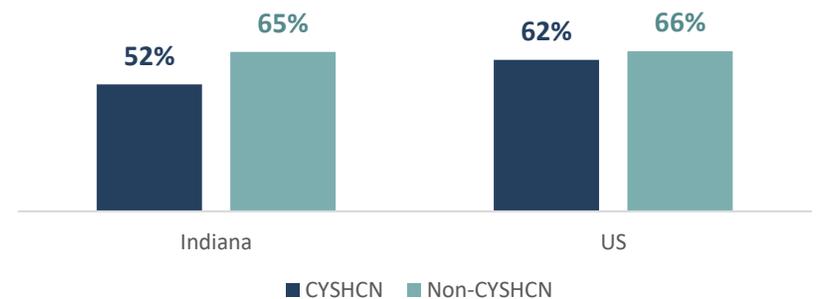
“A lot of the time I feel like [kids will] stay up all night studying instead of sleeping.” – **Barrier: School Responsibilities** (From adolescent focus group)

“We’re outsourcing an unbelievable amount of money to things. We’re hitting credit card after credit card because we don’t have the funds to pay on our bills and everything that we have to have to live.” – **Barrier: Income/Employment**

“I don’t necessarily have time.” – **Barrier: Other Priorities**

## Quick Facts

**Children and youth with special healthcare needs (CYSHCN)** (4 months to 17 years old) in Indiana are getting *less* than the recommended age-appropriate hours of sleep, compared to CYSHCN across the US and to **non-CYSHCN**.



Data Source: National Survey of Children’s Health, 2017-2018

\*\*Statewide survey data are from 2020 and focus groups were conducted in 2019 & 2020; both caregivers’ feedback about the needs of their child or young adult with special healthcare needs.

# Social/Emotional Development

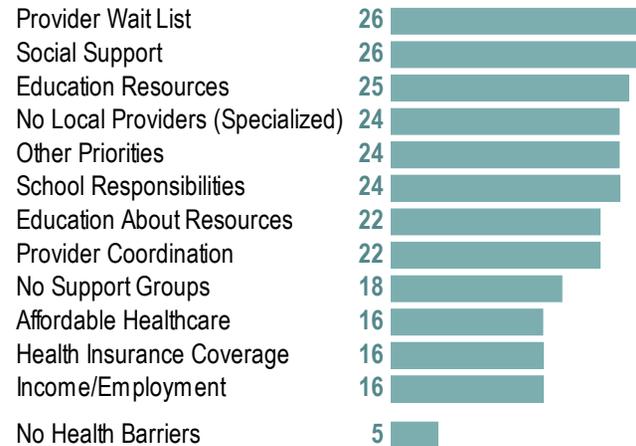
Young Child **#4**, Child **#3**, & Adolescent **#2**

*Definition: For young children, this can include making friends, showing emotions, or separating easily from parents. For children, this can include participating in group activities, being more independent, or showing sympathy. For adolescents, this can include confidence, self-esteem, independence, or healthy relationships.*

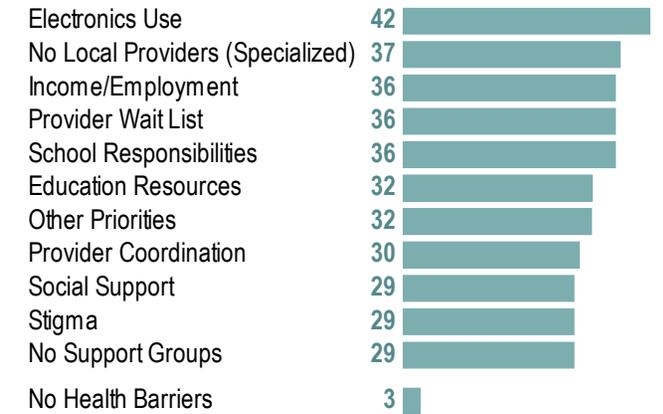
## Statewide Survey: Social/Emotional Dev. Barriers – Young Child



## Statewide Survey: Social/Emotional Dev. Barriers – Child



## Statewide Survey: Social/Emotional Dev. Barriers – Adolescent



## Focus Group Quotes

*“Our son would have benefitted from maybe some group or [something] in the schools... He’s just barely on the autism spectrum, but it causes [him challenges] picking up on social cues and things like that. He could have benefitted from having more counseling in school, or if there was a group therapy or something to help give him tools to understand how to relate to other people. I think that would be helpful for him and others like him.” – Social/Emotional Development*

*“Being able to teach him better to relate to people, give him those skills through speech or if you have a learning disability, skills to do better in school. He needed social skills. There’s no coaching for that. That’s an area that could be improved to help him fit in better. He didn’t need special ed. He just needed to better fit in, and it just seems like there’s a gap there for kids who are on the autism spectrum [but who are] not bad. If he was bad on the spectrum, there’d be accommodations for him, but he fell into a gap where there wasn’t anything to help him.” – Social/Emotional Development*

*“I’ve had to quit my job. We went through seven babysitters in six months, because they couldn’t handle her behaviors. So, I stay home with her and then [provide] transportation to therapy appointments. I don’t see how anyone can work full time and right now we’re in four therapies a week.” – Barrier: Childcare*

## Quick Facts

**48%** of Indiana Local Educational Agencies (LEAs) met targets (≥ 77%) for the percentage of preschoolers with IEPs who substantially increased their positive social-emotional skills. In 29% of LEAs, at least 27% of preschoolers with IEPs were functioning within age expectations (i.e., targets were met) (IDOE, 2020).

**63%** of Indiana children 3-17 with special healthcare needs who have a mental or behavioral condition received treatment or counseling (NSCH, 2017-2018).\*  
 \*estimate has a 95% confidence interval width exceeding 20 percentage points

*\*\*Statewide survey data are from 2020 and focus groups were conducted in 2019 & 2020; both caregivers’ feedback about the needs of their child or young adult with special healthcare needs.*

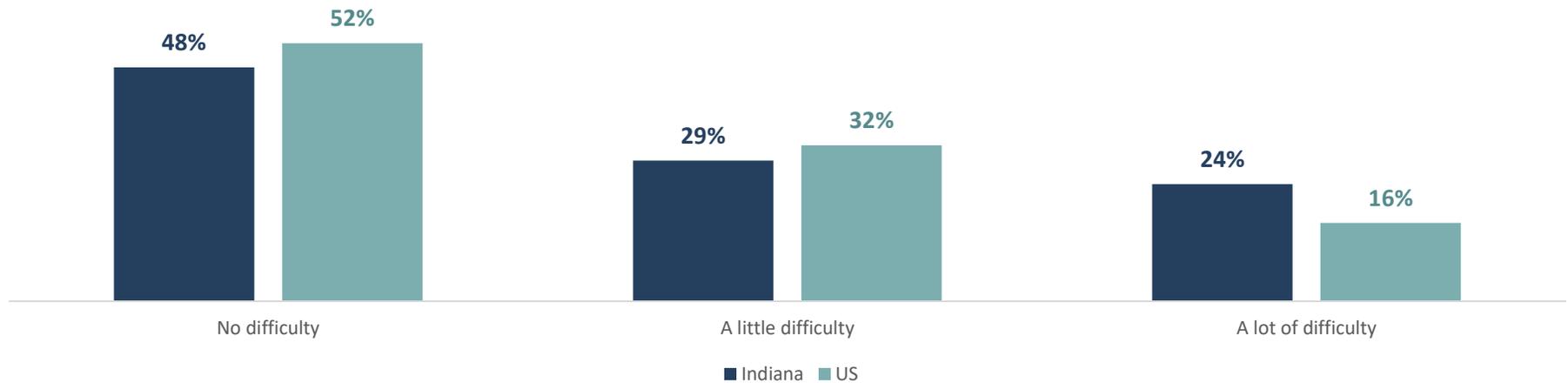
# Social/Emotional Development *(continued)*

Young Child #4, Child #3, & Adolescent #2

Definition: For young children, this can include making friends, showing emotions, or separating easily from parents. For children, this can include participating in group activities, being more independent, or showing sympathy. For adolescents, this can include confidence, self-esteem, independence, or healthy relationships.

## Quick Facts *(continued)*

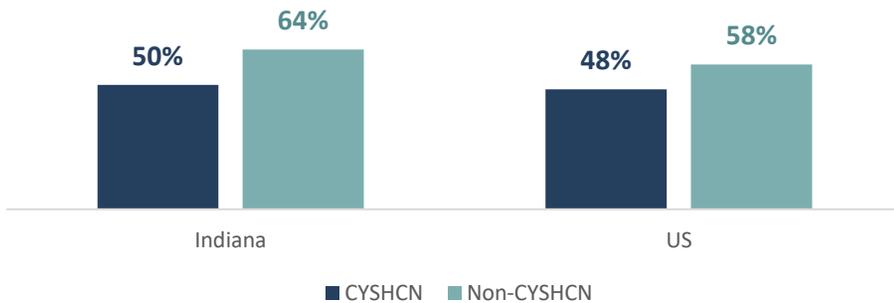
Children 6-17 years old with special healthcare needs in **Indiana** have greater difficulty making or keeping friends than their peers across the **US**.



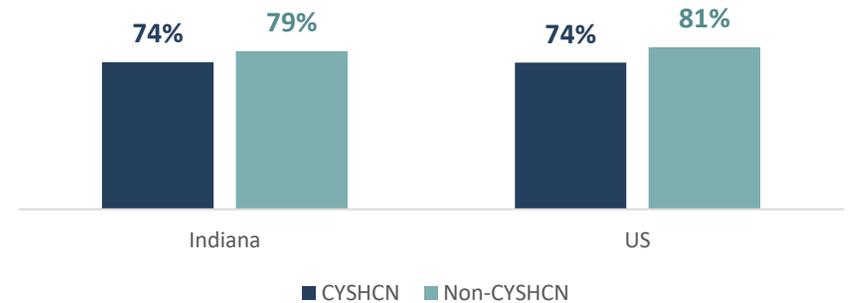
Data Source: National Survey of Children's Health, 2017-2018

**CYSHCN** 0-17 years old are *less* likely to live in a supportive neighborhood than **non-CYSHCN**.

**CYSHCN** 6-17 years old are *less* likely to participate in one or more organized activities or lessons afterschool or on the weekend than **non-CYSHCN**.



Data Source: National Survey of Children's Health, 2017-2018



Data Source: National Survey of Children's Health, 2017-2018

\*\*Statewide survey data are from 2020 and focus groups were conducted in 2019 & 2020; both caregivers' feedback about the needs of their child or young adult with special healthcare needs.

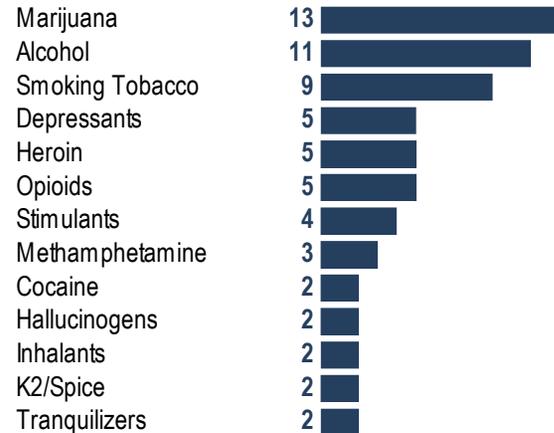
# Substance Use

Definition: Use of alcohol, drugs, or nicotine.

## Statewide Survey: Substance Use – Child

Less than 10 respondents identified Substance as a need for children. Due to the small number of responses, specific barrier information and a description of substance use in children are not included.

## Statewide Survey: Substance Use (Adolescent) – Described



All respondents selected at least one substance use option

## Statewide Survey: Substance Use – Adolescent



## Focus Group Quotes

“Getting into an appointment that’s after school hours [is] difficult, because they close at 5 and only have so many [openings] and they get booked up the fastest.” – **Barrier: Provider Wait List**

“We’re outsourcing an unbelievable amount of money to things. We’re hitting credit card after credit card because we don’t have the funds to pay on our bills and everything that we have to have to live.” – **Barrier: Income/Employment**

## Quick Facts

**28%** of Indiana children 0-17 years old with special healthcare needs live in a household where someone smokes. This is higher than children without special healthcare needs in Indiana (19%) and higher than CYSHCN in the US (20%) (NSCH, 2017-2018).

**45%** of all Indiana high school students and 21% of all middle school students have previously used tobacco (any product) (IYI KIDS COUNT® Data Book, 2020).

**35%** of all Indiana high school students have ever used marijuana (YRBS, 2015).

\*\*Statewide survey data are from 2020 and focus groups were conducted in 2019 & 2020; both caregivers’ feedback about the needs of their child or young adult with special healthcare needs.

# Trauma or Violence

Definition: Experiences of trauma or violence, including domestic violence, bullying, or cyberbullying.

## Statewide Survey: Trauma or Violence – Child



## Statewide Survey: Trauma or Violence – Adolescent



## Focus Group Quotes

“He’s high functioning, but very socially not on this level. Kids don’t want to learn all about the presidents like he does. That’s what he just goes on and on about. He gets bullied because of the ringing of his hands and the different ticks.” – **Bullying**

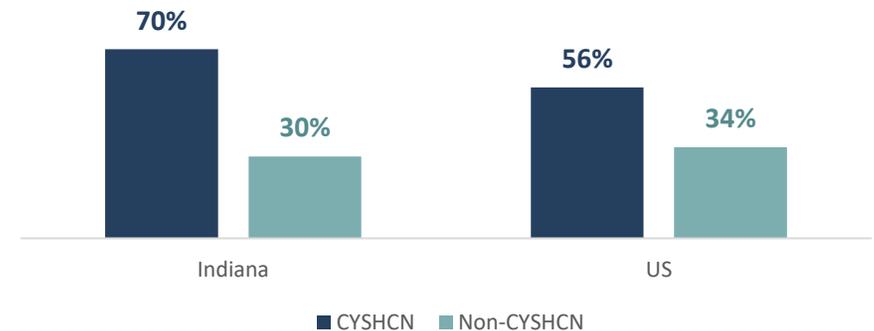
“Our son has went through bullying. Things like that... It still hasn’t stopped.” – **Bullying**

“I would say when we first started walking down this road [with our child’s diagnosis], we felt very, very alone. Very alone. I’m getting emotional. Very alone.” – **Barrier: Social Support**

“I mean the hardest thing is getting diagnosed and then having a waitlist. There’s a waitlist to be evaluated and now we have the diagnosis now there’s a waitlist for services and it’s like all this wasted time.” – **Barrier: Provider Wait List**

## Quick Facts

Children and youth with special healthcare needs (CYSHCN) ages 12-17 in Indiana are bullied more than both CYSHCN across the US and non-CYSHCN.



Data Source: National Survey of Children’s Health, 2018

\*\*Statewide survey data are from 2020 and focus groups were conducted in 2019 & 2020; both caregivers’ feedback about the needs of their child or young adult with special healthcare needs.